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ABSTRACT

This feature issue of a bulletin on community integration points out the challenge of making service systems more familiar with and responsive to the needs of older adults with developmental disabilities and their families. It includes articles with the following titles and authors: "Living on the Edge" (Arthur Campbell, Jr.); "Aging and Developmental Disabilities: State of the Art, State of the Need" (Thomas J. Lottman); "Disability, Aging, and Ethnicity: A Call for Inclusion" (Mariellen L. Kuehn); "Person-Centered Planning in Case Coordination" (Deborah J. Anderson and Alan Factor); "Person-Centered Later Life Planning: A Model" (Kathryn Heck and others); "No More Lone Rangers: It's Time for Collaboration" (James A. Stone and M. C. Martinson); "Welcoming Self Advocates" (Esther Lee Pederson); "Retirement of Older People with Developmental Disabilities" (Harvey L. Sterns and Evelyn Sutton); "Looking for Answers: Leisure Needs of Aging Adults with Developmental Disabilities" (Barbara Hawkins); "Integrated Leisure Options: The Peer Companion Model" (Ruth S. Roberts and Evelyn Sutton); "Aging Family Caregivers: Planning for the Future" (Tamar Heller); "Siblings: The Next Generation of Family Supports?" (Gary B. Seltzer); "Health Services for Older People with Mental Retardation/Developmental Disabilities" (Deborah J. Anderson and Patricia Moran); "Health Issues for Aging Persons with Down Syndrome" (Marilyn Adlin); and "Programming for Persons with Alzheimer's" (Bill Everett). A resources section lists three organizations and nine publications. (JDD)

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Feature Issue on Aging and Developmental Disabilities

Institute on Community Integration
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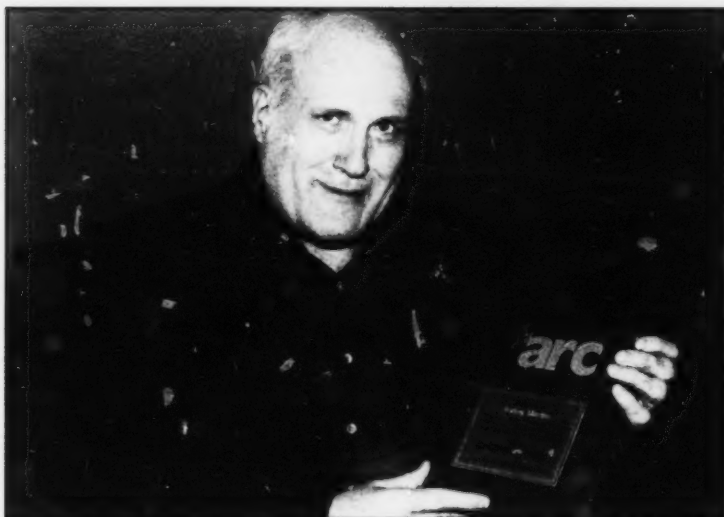
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Feature Issue on Aging and Developmental Disabilities

Volume 6 (1) Spring 1993



Irving Martin is one of many older adults with developmental disabilities who is, as his award from the Arc says, "...overcoming obstacles toward achieving success as a leader and contributing member of the community." Story on p. 7.

Living On the Edge

by Arthur Campbell, Jr.

This article is written from the edge. What am I doing on the edge? Edge of what? I am 49 years of age. I was born with spastic cerebral palsy. I am on the edge of being institutionalized for life.

When a person has spastic cerebral palsy it usually means that they have a very difficult time controlling their muscles. I have a variety of severe disabilities, including mobility and severe speech impairments. My disability is what government and other agencies call "developmental disabilities." In spite of my disabilities, I am quite capable of directing my own affairs.

I was born in 1944. Back then, our society did not believe in educating their disabled children, so I never had a formal education. In fact, up to this date I have been unable to get into any programs that serve disabled people. I am not saying that my parents did not try to get me into these programs, but they were from a very simple background. When they tried to get help for me every door slammed shut in their faces. This was due to two reasons. The first one was that until 15 years ago there were no programs for the severely disabled people; the second reason was that they were recently told that I am too old for the programs and there is too long a waiting list.

So, the first 39 years of my life I sat in the back bedroom of my parents' home. I did accomplish one thing in those 39 years: I taught myself to read and write. I have been informally tested and some of

Edge, continued on page 23

From the Editors

"The legacy of older persons with developmental disabilities is one of survival and life-long adaptation..." So concludes one article in *IMPACT: Feature Issue on Aging and Developmental Disabilities*. It is this legacy that is acknowledged, and the future that is addressed, in the pages of this issue.

As the number of individuals with developmental disabilities living past age 55 in local communities increases, service providers and policymakers are faced with a challenge. That challenge is to make our service systems more familiar with and responsive to the needs of older adults with developmental disabilities and their families. It is with that goal in mind that the information in this *IMPACT* is presented.

In these pages, readers have access to state-of-the-art information and service approaches. This issue was authored primarily by members of the RRTC Consortium on Aging and Developmental Disabilities. The consortium is a federally funded network of researchers in seven universities who are among the country's leading experts in the field of aging and developmental disabilities.

It is our hope that through this *IMPACT* readers will come to a new appreciation of the legacy of aging adults with developmental disabilities, and a new or renewed commitment to add to that legacy abundant opportunities for full lives.

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Aging and Developmental Disabilities: State of the Art, State of the Need

by Thomas J. Lottman

The field of aging and developmental disabilities has seen tremendous growth over the last few years. It has been growth not only in the volume of research, programs, and policy initiatives, but also in the sophistication of these initiatives. Five years ago in the Clearinghouse of the Rehabilitation Research and Training Center on Aging and Developmental Disabilities, it wasn't unusual for us to receive a request for "whatever you have on aging and DD." Now the requests are quite specific. In research, practice, and policy arenas, there has been a concerted effort to address the needs and issues of this historically overlooked and underserved population. This is the "state-of-the-art." While the state-of-the-art is impressive, we would do well to also consider the "state-of-the-need" of the population of older persons with developmental disabilities that has emerged from the cumulative body of research.

While it is impossible to adequately summarize research in aging and developmental disabilities in a brief article, it is possible and important to draw attention to one conclusion that has significant implications for future research as well as the translation of research knowledge into practice. This conclusion is that as persons with developmental disabilities age, they become, as a group, more like their age cohorts with disabilities and increasingly different from each other in preferences, needs, and functional competence. Aging does not "homogenize" the population of persons with developmental disabilities. This simple conclusion has profound implications not only for future research, but also for the planning of services.

From a research perspective, there are several directions for future studies implied in this conclusion. First, future research should be directed at identifying more homogeneous sub-groups within the population. Examination of differences with age between diagnostic groups, levels of early impairment, primary lifetime residential setting, ethnic groups, and gender must be a priority. Secondly, research methodology must give voice to the experiences of older persons with developmental disabilities as they age. To date, research data and findings have been mediated by caregiver respondents, agency records, or normalized assessment protocols. The field lacks an immediate view of the experience of aging from older persons with developmental disabilities and their families. Whatever the content area, our research process should describe and contrast the experiences of our research participants. Older people with developmental disabilities and their families also must be involved in the process of planning, implementing, and disseminating the research that will ultimately affect them.

For the service sector, the heterogeneity of the population also has significant planning implications. At the policy level, we must find innovative funding mechanisms to insure that dollars follow people rather than people following dollars. We need to develop a range of service options congruent with the spectrum of need and capabilities that characterize the population. At the systems level, we ought to increase collaboration between the aging and developmental disabilities services, recognizing the age-related convergence of needs of persons with and without disabilities. At the programmatic level we need to implement a "person-centered" approach to planning that meaningfully involves the older person with a developmental disability, their family, friends, and other supports in a way that is responsive to their individual preferences and needs. As we reject the historic "cookie cutter" approach to service planning, we must substitute a truly different way of thinking about service delivery and supports and not just change cookie cutters. A conceptualization of community integration should reflect the belief that "community" for all of us represents people and places that give us the opportunity to satisfy the needs for belonging and becoming, and that the locus of living, working, and recreating do not necessarily guarantee this opportunity. True person-centered planning involves not the assumption of preference, but the assessment of preference.

Both the state-of-the-art and the state-of-the-need in the field of aging and developmental disabilities compel a strong collaboration between researchers and service providers. The research endeavor must be extended into the lives of older persons with developmental disabilities through the transfer of research findings and technology to service providers. For this to be effective, service providers and others need to be involved in the planning of research.

Finally, the identities of older persons with developmental disabilities are defined neither by their age nor their disability, but rather by their personal history, current preferences, and future hopes. It is this identified person that participates in our research, and it is to this identified person that we deliver services. This fact must remain at the center of our research and service endeavors. The legacy of older persons with developmental disabilities is one of survival and life-long adaptation, and this legacy demands nothing less.

Thomas J. Lottman is Co-Principal Investigator for the RRTC Consortium on Aging and Developmental Disabilities, and is on the staff of the University Affiliated Cincinnati Center for Developmental Disorders, University of Cincinnati.

Disability, Aging, and Ethnicity: A Call for Inclusion

by Mariellen L. Kuehn

Most Americans are aware of the changing demographics within the United States and the growing proportions of both older people and people of color. The number of older people with developmental disabilities also is increasing, both among populations of color and among the non-Hispanic white population. Few of us have given much consideration to the implications of these demographic changes and the unique needs of older people with developmental disabilities who are members of racial/ethnic minority groups. While our focus has been on the passage of the Americans with Disabilities Act and total inclusion for all people with disabilities, minimal attention has been given to the need to include people of color who have developmental disabilities within our advocacy efforts. Unless we begin to focus on the inclusion of people of color as full partners in advocacy organizations and the policymaking structures of the aging and developmental disabilities networks, the striving for inclusion of people with disabilities as full citizens of the United States will have no validity.

During this past summer, I participated in a series of focus groups on aging and developmental disabilities with parents of older adults with developmental disabilities who were African American, American Indian, Chinese American, Hawaiian, Japanese American, and Mexican American. Focus groups were also conducted in four states with administrative leaders from state departments of aging, developmental disabilities, and/or mental retardation. Paraphrased excerpts from some of these focus group discussions may help to clarify the situation faced by older people with developmental disabilities who are members of racial/ethnic minority groups, and the need for inclusive advocacy efforts:

- "The problems of access in the minority populations are the same problems that we see among people with disabilities. If a person is older or has a disability, and is a minority, you have a double hit on that person."
- "African-Americans who are seniors, or have disabilities, are not included in many aspects of life or the quality of life scheme. Those people are left out across the board. I speak from the minority perspective: minorities have it two or three times harder than the rest of the population."
- "We have a group of older adults with children who are aging with developmental disabilities, who never had the option for services that are now available...who never necessarily had the option of a free appropriate education or access to services."
- "Culturally it has been, 'This is my responsibility as a family member, this is our way of dealing with it.' And they have kept their child at home for 50 years."

- "So many of our agencies have not been culturally sensitive. The workers who usually serve the minority sector are not usually of the same color or don't understand the language or don't understand the problems and needs. Instead, they are coming across the tracks, if you will, to give you a service. And how culturally sensitive and culturally competent can that person be?"
- "The trust factors in delivery of services to minority populations is a big piece: 'Are you bringing or are you coming to take?' So much of the minority individual's life has been a taking-away process as opposed to receiving."

One of the major themes of the focus group discussions was that the parents from racial/ethnic minority groups, who have older sons or daughters with developmental disabilities, have experienced strong racial prejudice and discrimination throughout their lives. As a result, they are often unwilling to trust or to use a service system that has been dominated by the white race. In order to reach out to this population, the members of advocacy organizations, parent groups, councils, and other policy-making bodies need to be certain that the membership of their groups is representative and inclusive of people with developmental disabilities from diverse cultures.

Outreach efforts can be initiated at both individual and organizational levels. One suggestion for outreach to African-American people is to contact local church groups, such as the African Methodist Episcopal denomination, which has its roots in the slavery era. The African-American community and many of the Asian communities also have their own newspapers and radio stations that could be used to advertise events. Posters or fliers about services and supports for older people with developmental disabilities could be distributed to American Indians at Pow Wows. Several states have started to use the *Educativa Festiva* model developed in California about 15 years ago as an educational forum for Hispanics. Another suggestion is to create a toll-free number that people can call to get information about services and organizations.

The need for outreach and inclusion of people of color will become more critical each year as the proportion of racial/ethnic minority groups continues to increase in the United States. In order to have training, service, and research programs that are relevant for all citizens who have developmental disabilities, we need to include people of color in planning and program development efforts at every level of the aging and developmental disabilities networks.

Mariellen L. Kuehn is Associate Director of the Waisman Center (UAP) at the University of Wisconsin, Madison.

Person-Centered Planning in Case Coordination

by Deborah J. Anderson and Alan Factor

In recent years, the growing self-advocacy and empowerment movements among people with developmental disabilities have been catalysts for moving the service delivery system toward a person-centered planning model. As service providers address the needs of the growing numbers of older adults with developmental disabilities, this person-centered approach acknowledges the importance of involving these older adults and their families in planning and in making choices about the future.

In 1991, a national survey was conducted of states regarding their developmental disabilities case management systems to determine the extent to which states are moving toward person-centered planning, factors affecting its implementation, and its implications for addressing the needs of older adults. The survey was completed by staff in 46 states' developmental disabilities agencies who are responsible for overseeing case management. The results revealed that while most states support some type of person-centered planning, the extent to which this philosophy is realized is less clear.

■ Existing and Planned Approaches

In the survey, person-centered planning was defined as a concept that:

- Recognizes the importance of involving persons with developmental disabilities and their families in planning and making choices about their lives.
- Recognizes that choices should be made based upon their knowledge of options and adequate information.
- Sensitizes family and staff to understand and facilitate choices and preferences of persons with developmental disabilities.
- Uses generic community services when appropriate to provide community integration; does not duplicate services.
- Encourages program options beyond the traditional developmental disabilities service system.

Forty of the 46 states surveyed (87%) indicated that they had or were planning to have some type of person-centered planning approach to case management or habilitation planning. In many instances, however, the extent to which a person-centered planning philosophy was realized in action was unclear. Many states responded that a variety of programs, or their overall planning processes, involved person-centered planning. Others indicated that some providers used person-centered planning in programs such as Medicaid Waiver and family support programs. Still others

indicated that plans were in the works for future person-centered programs or that these concepts were part of the guidelines for service.

States employed a variety of techniques that encouraged the active involvement of individuals and their families in coordinating services and in the habilitation planning process. Responses revealed the following:

- Virtually all states required the person with a disability and their relatives to participate in the habilitation planning meetings.
- Six states reported training family members as case managers to implement and coordinate services.
- Thirty-two states provided training in advocacy and empowerment for individuals with developmental disabilities and/or their families.
- Ten states indicated that they encouraged individuals and their families to invite other interested parties in addition to the Interdisciplinary Team (IDT) to attend the meeting. However, 20 states indicated that habilitation planning was driven by the IDT and linked to specific program models so that individuals and families actually had very little to say about their service options.
- Seven states noted that involvement in the habilitation planning process varied according to the abilities and interests of the individuals and their families.

■ Factors Affecting Implementation

All but one state indicated that person-centered approaches were feasible. In explaining their responses, many simply indicated that it had been in operation and was working effectively in some or all areas of the state. Others indicated that it worked because of a combined effort of the state agency, private agencies, individuals with developmental disabilities, and/or families. Commonly mentioned factors that had facilitated implementation of person-centered approaches were the state's administrative commitment and support for this model; the staff's commitment, interest and determination; strong support by families, consumers and advocates; funds specifically appropriated for it; training by persons skilled in person-centered approaches; legal or legislative pressures; and lower caseload sizes.

All states surveyed also identified the barriers to implementation. These included the following:

- Limited choices because funds are tied to the program rather than the individual.

- High caseloads.
- Insufficient service availability.
- Lack of advocacy training for individuals and families.
- Provider resistance to relinquishing power.
- Individual's or family's deference to service provider's professional judgments (although states which trained individuals and/or their families in empowerment and advocacy were less likely to indicate this).
- Lack of experience with the model.

Two of the most often mentioned barriers were limited choices because funds are tied to the program rather than the individual, and high caseloads. States that had some experience with using person-centered approaches were more likely to say that funds being tied to the program was a barrier than states without person-centered approaches. This funding issue particularly affects older individuals who may have age-related changes in stamina or interests that in turn affect the number of hours they wish to spend in day programs. If funding is tied to the individual, this permits greater flexibility in the time spent in day programs, in the community, and in their residence.

Thirteen states indicated that high caseloads were a problem. High caseloads as a barrier were more common in states without dual roles for case managers. When case managers performed the dual functions of case management and service provision (nearly two-thirds of states), caseload sizes were significantly lower, averaging 47 compared with 78 in states where case management was independent of service provision. The implications of this are unclear regarding time spent actually conducting case coordination functions. However, most providers considered the lack of independent case management to be problematic, citing a number of possible problems, including conflicts between the agency's needs for clients and the client's needs, limitation of the case manager's role as an advocate, conflicts of interest around monitoring, discouragement of creative and nontraditional service options, and blurring of lines of responsibility between case management agencies and direct service agencies.

When specifically asked what problems their states had encountered in implementing the person-centered model for adults with developmental disabilities, respondents indicated:

- Resistance on the part of providers to changing their attitudes and ways of "doing business".
- The needs for retraining staff, rewriting policies and standards, and more time to do so (e.g., the process is lengthy and requires sophisticated values and program planning expertise).
- Limited community resources and informal support networks for people.

- Concern about the extent of comprehension of individuals with developmental disabilities.
- Increased cost or lack of funds.
- An emphasis on family over individual.

Respondents also identified a number of shortcomings of the states' case management systems in meeting the age-related needs of older persons with developmental disabilities. These included possible problems in integrating effectively with aging agency services, access to generic resources in the community, the absence of specialized programs or services that focus on meeting the age-related needs of older adults, a lack of resources in the community (such as resources for people with Alzheimer's Disease), and regulations and understanding regarding active treatment/day program participation. Among the concerns about case management or person-centered planning that respondents felt particularly affected older persons with developmental disabilities were the following:

- Lack of knowledge about best practices and varying philosophical approaches to help the individual determine what is in their best interest.
- Difficulty identifying needs until a crisis occurs.
- Lack of family involvement due to age.
- Reduced expectations about what services should be available and how those services should be delivered.
- Limited program options beyond or within the traditional developmental disability programs.

■ Conclusion

Although progress has been made in the implementation of person-centered planning, states are facing the difficult task of trying to implement an individually-oriented, time-intensive planning process with funding structures that are limiting flexibility, caseloads that are prohibitively high, and case management structures in which there are inherent conflicts of interest. In addition, there are few specialized or generic services prepared to meet the special needs of older adults with developmental disabilities. The growing involvement of individuals with developmental disabilities and their families in the planning process is heartening, but it is tempered by the realities of scarce services, inadequate knowledge, crisis-oriented planning, and the added stigma of age.

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Person-Centered Later Life Planning: A Model

by Kathryn Heck, Tamar Heller, Alan Factor, Harvey L. Sterns, and Evelyn Sutton

When John and I first discussed "retirement" he looked at me with a blank face. At the age of 58, he had never even heard the word, let alone learned that it was an option for his future. When I explained that retirement would give him an opportunity to stop working and increase his leisure activities, he said, "I don't know how to do anything else."

When older people with developmental disabilities are faced with the option of retirement, many are not aware of the consequences of their retirement or of the alternatives. Additionally, many are not even provided the opportunity to participate in the decision-making process. Person-centered planning, which actively involves individuals with developmental disabilities and their families, has become increasingly common in services to children and young adults. Yet these same opportunities for empowerment and choice-making have been slow to develop for older individuals.

In response to this need, the Person Centered Later Life Planning project is being conducted by the RRTC Consortium on Aging and Developmental Disabilities. The project, involving older individuals with developmental disabilities, family members, and program staff, seeks to empower participants who have disabilities with the knowledge and skills to make life decisions. This is accomplished through training that has two main components: a) education that focuses on later life options and planning issues, and b) a planning process that focuses on individual empowerment issues and skills. The training addresses issues faced by the general aging population, including the maintenance of health/wellness, leisure activities, work options, and living arrangements. It also emphasizes choice-making, advocacy, and community integration.

Fifty-four individuals with developmental disabilities have participated in the training, which has been provided to 10 groups of four to six older persons with developmental disabilities through 15 weekly, two-hour sessions. Information about participants collected prior to training revealed that many had not been involved in the choice-making process in a number of daily activities. For example, 61% stated that they did not make any choices in the type of work that they did, and 26% reported not having a choice in something as fundamental as what to eat. The pre-training information also indicated that the participants had specific preferences about various areas of their lives. Considerable numbers expressed a desire to participate in specific leisure/recreational activities. Forty-six percent of those surveyed desired to join either an activities club or senior center. Over one-third of participants said that they would like to date, although they do not currently do so. Thirty-five percent indicated that they would like to go camping or learn to play a musical instrument. Work-related preferences included

the desire to retire from their job, which was expressed by 13% of the participants. Of that 13%, the majority stated that they would prefer to reduce the number of hours of work rather than retire completely. In regard to residential placement, nearly half aspired to live on their own.

Obviously, participants have come to the training with limited experience in choice-making, accompanied by clear preferences in some areas of their lives. The project has sought to facilitate their awareness of their options, their ability to select from among options, and ultimately their ability to be more involved in life planning as they age.

One aspect of the training that has been well received by participants is exposure to new experiences and opportunities for actual choice-making. For example, during the session on leisure activities, a variety of sports equipment was made available. Upon seeing a baseball and mitt, one 69-year-old gentleman grinned from ear to ear and said, "I've seen baseball on TV, but I've never *touched* a baseball mitt!" He was so mesmerized by the glove that one could see his thought processes. It appeared that for this gentleman, baseball suddenly made sense. It had a feeling, a meaning. In another example, when given an opportunity to participate in an exercise video, a woman who usually kept to herself decided to lead the group.

In addition to offering new experiences, the leisure activities session expands on current interests. For instance, one participant liked to garden, so the group planted some seeds. Another participant wanted a pet, so the group purchased a fish. During such sessions the trainers have observed the importance of choice-making. Even very basic choices, such as choosing the type of seeds to plant or a name for the fish, have been highly valued by the participants. Additionally, by sharing interests, the group members expand their knowledge of various hobbies and activities. Reinforcement of participants' interests validates their own abilities to make personal choices.

Other dimensions of the training include socialization techniques, community integration, and creative alternatives to work. Field trips are taken to a variety of community settings, including senior centers where participants are able to experience one alternative to working. Rather than just being told that retirement provides opportunities to socialize and engage in leisure activities, trainees actually participate in activities with the other senior citizens who attend the program. Retirement thus becomes a tangible experience that they can recall when asked to make choices and plans. Creative alternatives to working full-time are also discussed in the training. These include working part-time and attending a senior center part-time; volunteering at local community settings such as nursing homes, animal shelters, or churches; or engaging in personal leisure activities.

The final training session at the end of 14 weeks applies the knowledge learned in the previous weeks through a problem-solving session conducted jointly with the individuals with disabilities, family members, and staff. Meetings first take place with each participant to discuss the Individual Habilitation Plan (IHP), as well as the person's active role within the planning process. After reviewing the information, participants meet with the trainer, staff, and family and jointly develop personalized "action plans" based upon their preferences and desires. These action plans provide individuals with opportunities to make life choices that can be incorporated into the IHP process. Meeting with the individual prior to the staff meeting offers the person an opportunity to process available options and take an active role in the planning.

Training is not limited to participants with developmental disabilities. Professional staff and family members also receive training to sensitize them to the age related needs of older individuals with developmental disabilities and to the importance of greater autonomy in choice-making. Topics include the aging process, an overview of the aging curriculum, and demonstrations in person-centered planning. The goal is to better enable staff and family members to assist the individual with disabilities to make choices that affect their later life plans.

Currently, the outcomes of the training are being evaluated by a number of measures. Though the data for the entire project are not yet available, it is apparent that at the individual level many of the participants are experiencing benefits. For example, one woman in her late 60s is now a paid service volunteer in a foster grandparent program. A 61-year-old man who had been labeled "very quiet" prior to the training has since begun to initiate conversation with staff and peers. Another man in his early 60s has finally verbalized a longtime desire to date; staff are instructing him on social skills and encouraging opportunities for dating.

Finally, as a result of the Later Life Planning Project, John, who did not know what retirement was prior to training, has decided to attend a senior center once a week. As he says, "I can still work - but not as much - and get money, and take

new classes and make new friends!" John is looking forward to his IHP staffing which will be held soon. He is not only eager to speak up for himself at his meeting, but to make the choices that affect his future.

The Person Centered Later Life Planning project is housed at the Institute for the Study of Developmental Disabilities (UAP), University of Illinois, Chicago. Kathryn Heck is Research Specialist at the Institute. Tamar Heller is Principal Investigator with the RRTC Consortium on Aging and Developmental Disabilities, and Coordinator of the Family Studies and Services Unit at the Institute. Alan Factor is Co-Principal Investigator with the Consortium, and Project Director at the Institute. Harvey L. Sterns is Director and Evelyn Sutton is Senior Fellow, both at the Institute for Life-Span Development and Gerontology, The University of Akron, Akron, Ohio. Both are Co-Principal Investigators of the RRTC Consortium.



Later Life: One Vision

Irving Martin has a clear idea about what older persons with developmental disabilities deserve: "I believe that everyone should be challenged to the best of their ability level." That is certainly what is happening for Irving. At the age of 54 he works at the job he has held for the past 19 years, lives in his own home, and as a self advocate is improving the world for persons with disabilities.

The motivation for Irving's self advocacy is his vision for people with disabilities: "My vision is for people to feel comfortable making decisions for themselves, and secure in the knowledge that people are listening to them." He was the first self-advocate to be on the national Arc Board of Directors, and was Director-at-Large for Arc Minnesota in 1992. He is also involved with the self-advocacy group People First, and has served on advisory councils for the Institute on Community Integration (UAP), University of Minnesota.

Irving has spoken at many national and international conferences, and finds the opportunity to speak to groups very rewarding. He once spoke about his experiences to 1,000 people at two church services. "Most of the people knew nothing about retardation. It was satisfying to tell them of my experiences and break down some of their ideas about retardation. They listened and were impressed by what I had to say."

This past year Irving attended the signing of the Americans with Disabilities Act (ADA) with a friend who was excited that it would help immediately. Irving was more excited, however, for the children that will benefit from ADA a few years from now. "When I was young, parents never knew what was out there. Today the situation is better. The public doesn't try to hide the situation."

Irving Martin feels fortunate to have had opportunities for personal fulfillment and to make a difference in the world. He's working to ensure that all people with disabilities have those same opportunities.

Irving Martin was interviewed by Eric Kloos, Family Support Specialist with the Minnesota Department of Education, St. Paul.

No More Lone Rangers: It's Time for Collaboration

by James A. Stone and M.C. Martinson

Older individuals with developmental disabilities and their families have complex and multiple problems and needs. It is hard for service agencies to coordinate support for an older individual and/or family at any particular point in time. It is even harder to plan for age appropriate needs and to support family life cycle planning processes over longer periods of time. Yet, both are necessary.

No single agency can be all things to all people. No single agency can meet the complex needs of older individuals with developmental disabilities or their families in social, educational, medical/health, financial, vocational, retirement, and life planning areas. How well each agency coordinates and integrates with other agencies is the best measure of how effective they really are in meeting needs. This is the essence of collaboration.

Collaboration can be defined as processes that encourage and facilitate an open and honest exchange of values, ideas, plans, approaches, and resources across disciplines, programs, and agencies. It also enables all participants to jointly define their separate interests and mutually identify changes needed to best achieve common purposes (adapted from Crosson, et al., 1978). Collaboration does not require creation of new agencies or another level of bureaucracy to complicate an already disjointed service system. It helps existing systems, agencies, and the people in them to increase cooperation and coordination in supporting older individuals with developmental disabilities and their families.

Collaboration offers numerous benefits to older individuals with developmental disabilities, their families, and service providers. Benefits to individuals and families include:

- Increased effectiveness of individualized service planning.
- Increased ability of families to monitor and evaluate the effectiveness of services provided.
- Greater accessibility of services from any one agency as well as from multiple agencies.
- Reduced time needed to access services.
- Improved integration of services for individual family members with more general family needs.
- More direct and effective involvement of individuals and families in service planning and development.

Benefits to service-providing agencies include:

- A broader, integrated basis for needs assessment and service planning.
- Reduced duplication and competitiveness in use of agency authorizations and services.

- A broader basis of support for social policy development and for fiscal support from resource control bodies.
- A readily available vehicle for positive, proactive planning with reduced misunderstanding and bickering among agencies after program policy decisions have been made.
- Improved effectiveness in program monitoring and accountability, particularly in service impact evaluation.
- Improved fiscal management procedures.

Just as there is no single agency to provide all services to all older individuals with developmental disabilities or their families (or even to one individual and their family), there also is no single, fixed way to do collaboration. A starting point in establishing collaborative relationships between agencies is identification of the legal and statutory mandates at local, state, and federal levels that specify authorizations and responsibilities for the involved agencies. This information should be made available for mutual review. Translating these authorizations and requirements into related program objectives will be a helpful next step; this permits review among agencies and identification of gaps or overlapping services. Defining program functions and activities will also be necessary, as will identification of related fiscal and program resources.

After this groundwork is laid, negotiation and implementation of interagency agreements can begin. Possible joint activities (Wieck, 1989) for agencies include:

- **Planning:** Determination of total service delivery system needs, priorities, and structure.
- **Development of Operating Policies:** Establishment of the policies, procedures, regulations, and guidelines governing the administration of programs or projects.
- **Grants Management:** Administration of grants.
- **Programming:** Development of programmatic solutions to problems in relation to existing resources.
- **Evaluation:** Determination of the effectiveness of service in meeting individuals' needs.
- **Data:** Gathering, storing, and disseminating information about individuals.
- **Use of Staff:** Service delivery through the same staff.
- **Central Support Services:** Consolidation or centralization of support services such as auditing, purchasing, exchange of material and equipment, and consultation.
- **Outreach:** Systematic recruitment of individuals.

- **Intake:** Determination of eligibility and admission of individuals to programs.
- **Transportation:** Provision of transportation.
- **Coordinated Budgeting/Planning:** Budget development by a neutral party working with all agencies together or individually, or by the agencies without a neutral party.
- **Funding:** Funding of services by agencies.
- **Purchase of Service:** Formal agreements between agencies to obtain or provide service.
- **Information Sharing:** Exchange of information on resources, procedures, and legal requirements (but not individuals) between agencies.

These activities and concepts differ from what presently exists only in that they combine agency resources to provide improved access to programs and services.

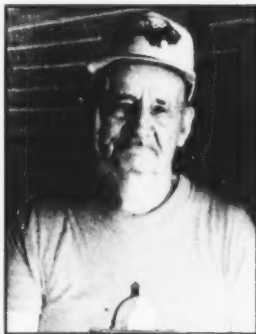
Collaborative planning is a continuing process. It cannot be done effectively through a short term, "I'm glad we got that done" approach. Relationships must be reinforced. Needs and demands change. Maintaining good collaborative relationships requires ongoing consensus building, review

and evaluation of service availability and quality, identification of barriers to achieving goals, implementation of strategies for reducing or eliminating barriers, and information sharing. Lastly, and most importantly, successful collaboration uses an individual and family referenced approach. It places priority on seeking out, and listening to input from older individuals with developmental disabilities and their families, and collectively responding to their concerns, preferences, and needs.

This article was adapted from the report, "Models for Interagency Planning for Long-Term Funding of Small-Scale Community Living Options for Older Persons with Developmental Disabilities," published by the Interdisciplinary Human Development Institute (UAP), University of Kentucky. James A. Stone is Director of Aging Projects and M. C. Martinson is Executive Director at the Institute.

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A Testimony to Collaboration

In 1985, Comprehend, Inc., began its elderly mental retardation/developmental disabilities program. The program's goal is to serve persons with mental retardation/developmental disabilities, age 55 and older, by providing the opportunity for choices of social, recreational, residential and economic services available in the community. Bill was one of the original participants in this program.

At the time of his enrollment, Bill was 64 years old and living alone on his Social Security income. He had mild mental retardation and multiple medical problems, including a coronary pacemaker. He was unable to read or write other than his name. Bill had lived all his life in the same town and worked as a laborer at local businesses for many

years. He spent his leisure time aimlessly wandering the business district and making spontaneous visits to the personnel at offices and stores. He was a lonely man, well received by everyone, but considered a "likeable nuisance."

As he enrolled in the Comprehend program, Bill met with a case manager to identify his needs. The case manager then started contacting agencies and services. One of the first results of this effort was that Bill was able to move into a three person mini-home within walking distance of the business area. The mini-home provider assisted him with personal care and financial guidance. Bill paid off the debts he had accumulated with local stores and learned better management of his personal funds, an area that had caused problems for him in the past. His case manager provided transportation for his medical care, and also encouraged him to attend senior citizen centers three days per week. Bill became involved as a helper at the senior center and was there for nearly every event.

As a result of the assistance available through the Comprehend program, Bill found a more productive and socially valued place in his community. His wandering around the town was decreased to a minimal level, he contributed to the operation of the senior center, he dated, and he made new friends who accepted him for what he had to offer.

Bill passed away in January 1993. He was one of the first three participants in the program. Comprehend is a regional mental health/mental retardation agency serving a five-county area. This article was contributed by Marcia Arnold, Case Manager with Comprehend, Inc., Maysville, Kentucky.

Welcoming Self Advocates

by Esther Lee Pederson

Historically, people with mental retardation/developmental disabilities (MR/DD) and their family members have had to struggle to be heard. Today, more and more consumers are speaking out for themselves, but the boards and committees they are trying to influence are not always listening. While it has been recommended that at least 25% to 50% of the members of decision-making bodies be consumers, in reality many boards and committees do not

Today, more and more consumers are speaking out for themselves, but the boards and committees they are trying to influence are not always listening.

meet this standard and do not require the involvement of people with MR/DD or their families.

For some groups there is clearly no question as to the importance of including individuals with MR/DD and their family members in decisions that determine their own futures. There is, however, a question as to how their voices might best be heard in order to influence policymakers, researchers, and service providers. Acceptance and inclusion of their ideas is not accomplished overnight, and some efforts are more successful than others.

Adaptations and accommodations that enable people with MR/DD to become effective leaders often benefit other committee members with or without disabilities. Some steps that groups have taken to prepare for the inclusion of new members with MR/DD are: changing their language so that it is "cognitively accessible" or understandable to the entire group; slowing the pace of the meeting; taking time to get to know the new member(s); and drawing the member(s) with MR/DD into committee activities and discussions.

Meaningful participation goes beyond mere presence. Tokenism can exist if the group fears placing decision-making control in the hands of people with disabilities. To prevent this, a commitment and partnership of all working together is required. Members with MR/DD and their families should not be recruited simply because they have a disability, are related to a person with a disability, or because the group must meet a mandate or a requirement. They should be recruited as potential leaders because of their interest, life experiences, and/or expertise. Selection of new members should be based upon matches between their capabilities and interests and the mission of the group, with the expectations for the members with the disabilities not exceeding those for other members.

Qualities generally exhibited by all leaders, including leaders with MR/DD, are assertiveness, self-determination, decision-making skills, ability to work with others, the desire to share, and belief in the common vision of the group. For people to achieve these skills, they have to first believe that they can be effective in the role they have accepted; they also have to be willing to put the necessary time into learning how to become contributing members. One strategy that is useful for some individuals is for them to initially become involved on a task force to practice skills before they join a full committee. Over time, supports are identified and faded out, skills developed, and roles and responsibilities increased as the individual gains greater ability, comfort, and experience in the role of decision maker. Another approach is to provide supported leadership. This option encourages the person to select a partner to help. The partner then offers tutorials or pre-meetings and provides the opportunity to practice parliamentary procedures and other roles of the group. Yet another alternative is to establish co-leadership positions in which two people assume responsibilities normally carried by a single person. This helps to lessen the fear of a new role or responsibility.

Tokenism can exist if the group fears placing decision-making control in the hands of people with disabilities.

Sometimes financial support is necessary for the participation of a member with MR/DD or their family. It may be necessary to pay for an experienced person to provide support and training, or to reimburse members for transportation expenses or time away from work. Addressing these financial needs, as well as individualized support needs, is very important in ensuring active participation.

By taking steps to recruit, involve, and retain persons with MR/DD for policymaking, research, and service bodies, everyone benefits. This equal decision-making partnership results in personal growth and increased empowerment for individuals with disabilities and family members, and in a greater sensitivity by professionals to the value of listening to consumers.

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Retirement of Older People with Developmental Disabilities

by Harvey L. Sterns and Evelyn Sutton

Retirement for the general population has become established as a stage in the lifecycle of the average American. Although fluctuations in the economy may affect the decision, most workers leave the workplace between their mid 50s to mid 60s. This can mean second or third careers, extended leisure, new activities, and hobbies. Ten to twenty percent of older workers, depending on the occupation, wish to continue to work beyond traditional retirement age. Of those who retire, many (40%) say they would like to work part time. Health, income, attitude, preparation and the opportunity for choice all influence the decision to retire as well as the adjustment to retirement.

Retirement for older persons with mental retardation/developmental disabilities (MR/DD) presents a different picture than that for the general population. While state practices have varied, most older persons included in the MR/DD service system have only experienced sheltered work since deinstitutionalization began in the 1970s. Placement in sheltered workshops or, for a limited number, in supportive employment, was one consequence of deinstitutionalization. Before this "new era," many people worked in the institutions. This was primarily in service or agricultural tasks related to the functioning of the setting until peonage laws made such practice illegal. For those who never left home, employment was not common. Thus, work histories leading to a possible retirement are brief and more sporadic for older adults with MR/DD than for the general population, and, in some cases, virtually non-existent.

A study (Sutton, Sterns, & Schwartz, 1991) was conducted in 1989-1990 to examine aspects of retirement for persons over age 55 with mild to moderate developmental disabilities and a work history. The primary goal of the research was to see what options existed for retirement from sheltered work, day training programs, or other employment. The study surveyed 88 Ohio counties; Ohio is one of the few states offering retirement options for those over age 55 who have developmental disabilities. Sixty-three counties responded, representing 1,482 individuals over the age of 55. That number is approximately two-thirds of all known older persons in the MR/DD system statewide. Two-thirds of the sample were over age 60 and one-third were 55-59 years old.

Interestingly, this study found that most of these individuals still engaged in full-time or part-time work. Many who were working part time reportedly spent some time in "senior" groups within the MR/DD system, which

offered a variety of leisure and recreational activities. Fifty-one percent of those reportedly retired or working on a reduced schedule were participating in programs at community-based senior centers and nutrition sites. Churches, parks and community recreation programs were also utilized.

Still, the study suggests that in many ways life in retirement is not greatly changed for these older adults. Of the 595 subjects reported to be fully or partially retired, nearly all still traveled on their pre-retirement schedules to their former places of employment. Once there, they may have

engaged in the same work routine as in earlier years, divided their time between work and leisure activities, or spent the day in a series of specially planned activities. These activities included exercise, discussion of current events, and food preparation. Special outings and trips were reported by three-fourths of the counties in the study.

One condition that may present an advantage for the retiring older person with MR/DD is the built-in option for part-time or phased-down work. Such a choice appears to be popular in the Ohio counties, where researchers found that most of those over 55 had chosen a slower paced, shorter workday, with components of leisure balancing their reduced hours at the sheltered work site. In many states, the MR/DD system is well structured to accommodate this preference.

The Ohio results are not necessarily identical to those that would be found in other states. Each state must carefully study its own needs and resources in planning services for this older population. A study now in progress at the University of Illinois at Chicago and the University of Minnesota focuses on identification of states providing innovative programs and services for aging persons with MR/DD. This and other research will certainly improve our growing understanding of the picture nationwide.

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Looking for Answers: Leisure Needs of Aging Adults with Developmental Disabilities

by Barbara Hawkins

Access to and inclusion in the full range of leisure activities will grow in importance for people with developmental disabilities as they live longer and face many years of retirement. Numerous researchers have investigated the contribution that leisure activities make to life satisfaction in older adults in the general population. While this relationship between leisure and life satisfaction has been well documented for adults without developmental disabilities, for those with developmental disabilities it has just begun to receive attention.

For the aging population in general, social behavior becomes increasingly less related to work and more related to leisure activities. The importance of continued social connections through leisure is reflected in a higher level of life satisfaction accompanying higher levels of activity participation. Experts from the mental retardation field have suggested that, when combined with other social factors such as friendships, residential placement, and opportunities for community inclusion, leisure activity choices contribute to life satisfaction and well-being in individuals with developmental disabilities, as well.

The relationship between leisure activities and life satisfaction was examined, and its complexity illustrated, by a recent study (Hawkins, Eklund, & Martz, 1992) at the Institute for the Study of Developmental Disabilities, Indiana University. The study examined the leisure involvement and life satisfaction of 128 individuals with moderate mental retardation. The participants in the study represented two distinct groups: half ranged in age from 32-56 years and had Down syndrome, and the other half ranged in age from 52-79 years and had mental retardation not caused by Down syndrome. There were equal numbers of males and females in the study. Participants' current leisure activity involvements, preference for increasing involvement, interest in initiating new leisure activities, and constraints that impeded engagement in desired activities were evaluated. Additionally, life satisfaction was assessed, which included friendship and free time satisfaction, satisfaction with services, community satisfaction, general satisfaction, work or retirement activity, happiness and worry, and self-perceived health.

The results revealed that age was a significant factor in leisure activity involvement and life satisfaction for all participants. Older subjects experienced significantly lower life satisfaction and were engaged in fewer leisure activities

when compared with younger participants. For those with mental retardation due to causes other than Down syndrome, the correlation between leisure participation and life satisfaction paralleled that in the general population of aging adults: the higher the level of activity participation, the higher the perceived satisfaction with life. In contrast, the connection between life satisfaction and level of leisure activity involvement was less clear for persons with Down syndrome. The participants with Down syndrome showed significantly less

desire to increase their involvement and had less interest in initiating involvement in new activities. Yet, they remained similar in degree of life satisfaction to participants without Down syndrome. The cause of this difference is unclear.

As this study illustrates, older persons with developmental disabilities do not necessarily have leisure activity needs identical to those of their age peers in the general population. Additionally, there can be significant differences in needs and experiences within the population of persons with developmental disabilities. Clearly, there is a need for much more study in this area and answers to questions such as, "What are the leisure needs of various groups of persons with developmental disabilities?", "Are these aging individuals receiving adequate opportunities to engage in familiar activities and try new activities?", and "In what ways does level of involvement in leisure activities relate to life satisfaction for different individuals?"

As the number of aging persons with developmental disabilities continues to grow, so will the demand for opportunities to experience meaningful retirement years. To meet this growing demand, we must learn more about the leisure characteristics, experiences, and needs of this portion of our population. With that new knowledge it will then be possible to develop leisure options that offer all aging adults with developmental disabilities daily choices to pursue involvement, happiness, and well-being.

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Integrated Leisure Options: The *Peer Companion* Model

by Ruth S. Roberts and Evelyn Sutton

Older persons with mental retardation and developmental disabilities (MR/DD) often have a long history of social exclusion. Studies in the 1980s reported that this population has experienced a lifetime of isolation and segregation, including systematic exclusion from public school education, many years of institutionalization, and loss of family support. One approach to correcting this situation has been attempts by staff at local mental retardation centers to take van loads of older persons with MR/DD to senior centers. However, this strategy has frequently resulted in additional rejection and isolation.

In response to the need for the integration of older persons with MR/DD into the social lives of their communities, Project Access at the University of Akron implemented the Peer Companion model. The model uses senior volunteers from the community to serve as escorts for older adults with MR/DD entering community activities. The outcome of this approach is that instead of groups of older persons obviously shepherded to community activities by young staff members, two persons of similar age attend community activities as two friends.

Looking back over seven years of the program, it is clear that this strategy does work. Many of the pairs have continued as friends. For example:

- Virginia and Millie continue to see each other at least once a week to bowl or help in a preschool center for children with disabilities.
- Miriam and Lottie have just celebrated their fifth year of getting together. One of their favorite activities is visiting Miriam's sister.
- Dorothy and Ruth, in addition to many other activities, spent a week at an Elderhostel that featured music in which they are both interested.
- Bill and his friend Vernon go fishing when the weather is right; at other times they go to senior centers or malls.

A formal evaluation of the project conducted in 1991 reported four other positive trends for participants: 1) improved use of language; 2) improved personal care; 3) increased number of identified friends; and 4) increased participation in a greater variety of activities in the community. Sixty-nine percent of the agency personnel returning surveys indicated that they had observed positive change and improvement in participants' communication since the beginning of the project. Eighty-eight percent indicated that their clients initiated conversation more often, reporting on activities enjoyed with the new volunteer friend and in other ways referring to the new friend. Sixty-five percent reported

improvement in the client's interaction with peers in workshop or group home settings, and in senior centers.

The Peer Companion model is one that has been implemented around the country. It can work in virtually any location. There are five critical factors in the establishment of such a program:

- Development of a written statement supported by the service systems involved in the program. The statement sets forth the goal of the program: to serve as many older individuals with MR/DD as possible by providing a companion for a wide range of community activities.
- Identification of the older persons with MR/DD who may benefit from community activities in the company of a peer companion. This involves assessment of interests, strengths, and needs. Referrals typically come from workshop supervisors, residential personnel, or families.
- Recruitment of volunteers. This includes distribution of fliers through organizations and community settings where older persons may see them. Title V programs funded under the Older Americans Act are a possible source of volunteers in many communities. Title V funds low income older adults in community employment.
- Training for volunteers, staff, senior center leaders, and the participants with MR/DD. All need to understand the expectations and anticipated outcomes of the peer companion approach.
- Supervision and ongoing education to maintain the program. The coordinator should keep suggestions and ideas for appropriate community activities flowing toward the volunteer companions, who may take the lead in making plans with their partners.

The Peer Companion model is not only a strategy for facilitating mainstream integration of older adults with MR/DD, but more significantly it is a route to real friendship and an expanded support network for those who participate. The community volunteers have frequently pointed out that the process is a two-way street. Many have indicated that the experience has been important and beneficial to them. As one commented, "I hope that I can continue to have an impact on services for older people with mental retardation. I love Betty and she has contributed to a better life for me."

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Aging Family Caregivers: Planning for the Future

by Tamar Heller

Most families of persons with developmental disabilities provide lifelong family-based care for them. Although out-of-home placement increases as parents age, it is not the predominant living arrangement for persons with developmental disabilities until parental death or disability occurs. Two major concerns faced by these families are: Can they continue providing care in their home? What plans are in place for their relative's future when they can no longer provide care?

The Illinois University Affiliated Program in Developmental Disabilities, University of Illinois at Chicago, has undertaken a major program of research focusing on these transition issues for older caregivers. We have interviewed nearly 200 older caregivers in Ohio, Indiana, and Illinois, and over 40 of their relatives with developmental disabilities regarding their current quality of life and their future plans. We also conducted focus groups with family members and providers. The findings of this research reveal the needs and issues faced by these families, and point out directions for service networks to take in working with these families.

In continuing to provide care in their homes, families expressed both joys and frustrations. For most caregivers, the member with developmental disabilities provided meaning and purpose to their lives. One mother wrote about her son, "He has given my life meaning. He has taught me greater love, compassion, patience, and given me a different perspective on life's values." Another wrote, "My son is the son I always asked the Lord for. I have never felt handicapped or held back from anything in caring for and loving him. He is truly loved by all who know him."

For many elderly parents the adult child with disabilities provided needed help. This help included compassion, household chores, and personal care. For example, a man with moderate mental retardation in his 60s was caring for a 90 year old mother who was blind and incontinent. His brother, who lived nearby, would come in and check on them regularly. The following comments illustrate the help received by many of the parents we interviewed:

- "I am going on 70 years old, and have slowed down some, so my daughter's interest in wanting things nice and clean is very helpful to me as our home is large; it always looks nice because she is so helpful."
- "I am very ill and in poor health since the last year. Right now my son is more help than I am to him physically. Mentally, I still have to be always around him, be his pillar which he depends on."
- "She has a good sense of humor, is sharp-witted and contributes greatly to our daily conversations."

Some families expressed their frustrations with the caregiving demands and their lack of personal time for vacations after retirement:

- "The physical aspect of her care is more difficult for us as we get older; we need time to be alone."
- "She has reached an age where most of her friends she associates with through her Bible study group are now marrying and having children and she has become very angry and envious and as a result is becoming more difficult to deal with."
- "The most difficult problem facing us soon seems to be that we will have a problem finding a caretaker for our son if we travel a lot."
- "We were able until recent years to take our child with us on vacation. However, he is now unable to travel very far; his physical condition has worsened and he is in constant pain. We are unable financially to go on any extended vacation, which we do need badly from time to time, away from our disabled child."

As can be seen in the above comments, family caregivers varied widely in their ability to continue caregiving in the home. We found that the caregivers who experienced the greatest burden were those who had a family member with maladaptive behaviors and those who had low levels of support from their other relatives and from the service system. Siblings of the person with disabilities often played key roles; some were primary caregivers, caring for their sibling in their homes. Often siblings were designated as future caregivers when parents could no longer assume responsibility. Over the two years of our research we found that as the caregivers aged, their social supports decreased; several became widowed, and others noted less support from other relatives.

With the exception of day program services, the families used very few formal services. The highest unmet service need was for information on residential programs. Other high unmet service needs were for respite, social/recreational services, care management, information on guardianship and financial planning, and family counseling.

The major concern voiced by most of the families was planning for the future when they could no longer provide care. Most families found planning to be highly anxiety producing. Some of the difficulties included lack of acceptable residential options; lack of information regarding financial, residential, and legal aspects; and reluctance to burden other children. Many parents did not feel comfortable discussing future planning with their child with

disabilities. Some examples of their concerns are:

- "I have cared for my daughter for 37 years. I want her to learn to be away from me so that the trauma of my death will be lessened. I feel that I do not want to burden my son and daughter with her constant care."
- "I worry about if I should lose my health, what will it be like for her."
- "We as parents hope for placement, although we have tried for 30 years. We have applied for placement since he was about 30 and our personal experience has indicated the following: 1) Until more recently, there were no appropriate facilities for his needs; 2) If there are any correct facilities, we have not been so advised; 3) Some of the places we have seen are unfit for human occupation (he was placed for seven months and the conditions were intolerable). Some of our answers will make you think that we are too difficult to please - this is not so; we would be happy to find a decent, responsible home for him."
- "She has been our main concern in life in taking care of her - but our years of life are fast coming to the end for this, and other arrangements will have to be made. I have not been able to do this as yet. If one or the other should die, the decision would have to be made, because as a team we can manage, but alone we will not be able to carry the load."
- "Our son needs supervision, but can take care of himself very well. He would be happier in a group home than in the homes of his brothers with their teenage children. There is no home available for him now."

Our research indicates the need for family support programs serving families of adults with developmental disabilities living at home, and development of residential options for those needing out-of-home placements when families can no longer provide care in the home. Funding for family support initiatives has grown over the last decade. However, many of these programs limit family support to families with children rather than adults.

In Illinois, one example of a recent family support program that is being used by older family caregivers is the Home-Based Support Services Program that is providing services to 211 adults with developmental disabilities. Over half of their family caregivers are over age 55. This program offers up to about \$1200 per month of services determined through support plans. These are developed on an individual basis and provide flexible services ranging from respite care through friends or family to musical training in the home. However, the need for such services clearly surpasses the availability of funds. In a study conducted at the University of Illinois (Heller, Smith, & Kopnick, 1992), the differential effect of this support program on older versus younger caregivers of adults with developmental disabilities was studied over a six month period. The findings were that the

older families benefited more from the program than the younger families over time in comparison with a control group of nonparticipants. For example, the older program participants were more likely to show decreases in perceived caregiving burden and were more likely to establish guardianship. They also expressed less need for out-of-home placement of their relative in the near future. One older parent participating in the program noted the following benefits: "The stress of balancing a limited income and budget did not allow for what we are able to do now. The care provided makes living easier and a little less painful. Our worries are lessened, we are cheerier and less burdened, and fatigue is diminished. We are grateful to be part of the program. It gives worth to the individual." Another parent noted, "The program has freed up our finances so that our son could get service we could not afford before. We got much needed transportation, dental treatments, and therapy, and we arranged for guardianship. It has given me peace of mind."

For families requiring placement out of the family home, there is a need for other alternatives. Often families approach the service system for emergency placement after the illness or death of a family caregiver. In such cases families face long waiting lists and few acceptable options. A recent Arc study in 45 states indicated that over 64,000 persons with developmental disabilities were on waiting lists for residential services.

The findings that families have great difficulties planning for their relative's future, and that they have high needs for information on potential options, argue for improved case coordination and staff and family training in this area. Although future planning may generate short-term stress, it may lead to long-term comfort and smoother transitions. However, long-term plans made by families cannot assure smooth transition given the gaps in the available services. The service network can assist families in making future plans that include residential, financial, legal, and support services and that truly involve persons with developmental disabilities and key family members in decision-making.

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Note: Portions of this article are taken from an article entitled, "Family caregivers: Current and future concerns" in *Directions*, the Illinois Planning Council on Developmental Disabilities newsletter, November 1991.

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Siblings: The Next Generation of Family Supports?

by Gary B. Seltzer

"I feel at times that my life is no different than anyone else's, but that nagging is always in the background. When I grow older, my brother will always need some help and guidance. He won't go off and get married. I love him dearly, but he will always need my help. My parents are getting older and I think they expect me to take more responsibility when they can no longer or when they die. We never talk directly about this, though and I'm not sure I want that responsibility."

This quote was one of many collected in a 1991 study on siblings and parents of adult family members with developmental disabilities (Seltzer, Begun, Magen, & Luchterhand, in press). This sister's sincere concerns about her role as the future caregiver/guardian for her brother is not uncommon. It is estimated that almost 80% of individuals with developmental disabilities live with their families. Furthermore, estimates are that only about 40% of this group are known to the service system. Like the American populace in general, a significantly larger number of persons with developmental disabilities are living into old age. The next generation of likely caregivers for these individuals will be their siblings.

Recently, particularly in the gerontological literature, investigators have begun to note that siblings can have a profound effect on each other's development throughout the life course. Sibling relationships occupy a unique position within the study of human relationships. They are of potentially longer duration than any other human relationships, beginning with the birth of the second child and persisting until the death of one sibling. It is not uncommon today to find a sibling relationship that has persisted for 80 to 90 years. In addition, the sibling role is ascribed - usually by a common genetic, cultural, and experiential milieu - rather than achieved. It remains a part of an individual's identity regardless of changes in life circumstances. Furthermore, research on aging and sibling relationships suggests that the intensity and level of reciprocal involvement of siblings increases in older age. Although these patterns of interaction have been replicated in several reports of sibling relationships in later life, there has been no study of how these relationships may be similar or different when one of the siblings is a person with a developmental disability.

Sibling relationships are particularly important for older persons with developmental disabilities because, as a rule, they do not marry; if they do marry, they often do not have children, who are the primary support system for older people in general in our country. Their non-service system supports are often siblings with whom they have maintained a life-long relationship.

Traditionally, studies on siblings with developmental disabilities have focused on the developmental risks to the

non-disabled siblings of having a sibling with developmental disabilities. This approach is directed towards analyzing family or individual deviance as a result of living with a member with a disability. In addition, the majority of these studies covered the sibship relationship only during the period of cohabitation in the family of origin, that is, during childhood and adolescent years. Little is known about the variety of roles that siblings adopt in relationship to each other during adulthood, and in particular during old age. For example, little is known about the factors that either impede or mediate the transfer of the caregiving role from parents to siblings.

As noted, one reason to increase our understanding about later life relationships among siblings with a brother or sister who has a developmental disability is that siblings assume or are expected to assume the responsibility of caregiving when the parents are no longer able to do so. One of the few studies that has looked at sibling relationships across a wide age range (12 to 69 years of age) reported numerous age-related differences in the relationships between siblings (Begun, 1989). For example, siblings who were several years older than the sibling with a developmental disability were more satisfied with the sibling relationship than those several years younger than the sibling with a developmental disability. Similarly, another researcher also found that reports of the quality of sibling relationships differed at various points in the family life cycle. Again, older siblings, in this case middle-aged siblings, were perceived by their sisters and brothers with developmental disabilities to be closest and most supportive; the younger adult siblings without developmental disabilities were perceived as being less dependable.

Even when parents remain the primary caregivers, siblings tend to assume more responsibility for their brother or sister with a developmental disability as the parents and the individual age. In a data analysis conducted on a large number of caregiving mothers (Seltzer, Begun, Seltzer, & Krauss, 1991), it was found that mothers between the ages of 55 and 85 who reported feeling less stressed and less burdened by caregiving were those who experienced a high degree of social interaction between their children with and without developmental disabilities. That is, the quality of sibling relationship seems to affect the mothers' well being. Furthermore, the majority of mothers expected a sibling to assume the responsibility for their brother or sister after the mother was no longer able to provide care or supervision. Indeed, mothers who had made explicit plans for siblings to assume caregiving responsibility reported significantly less stress than mothers who had not made such arrangements. It is important to note that these findings report on the

mother's voice and not those of the siblings with and without disabilities. These adult children may not feel as their mothers do. Still, the gerontological findings reported earlier do suggest that as the sibship ages, relationships seem to improve and become more supportive.

Thus, there are compelling reasons to include siblings among the caregiver group that needs to be studied and supported. The array of questions to explore are numerous, including:

- What are the types of caring roles that these adult siblings play with their sibling with developmental disabilities (direct care, advocacy, other social supports, financial supports)? How can we support these roles?
- How does the sibling with developmental disabilities fit into the brother or sister's present family of origin (his/her spouse, children, etc.)?
- How much do the siblings retain the child-to-child roles of earlier years? This pattern might result in a brother or sister treating the sibling with developmental disabilities as less competent than he or she actually is, and in turn, the sibling with developmental disabilities acting less competent in order to maintain the relationship.
- What are the knowledge and attitudinal gaps that exist among siblings without developmental disabilities, gaps that may impede the sibship from seeking appropriate services and life experiences?
- What are the interrelationships among multiple siblings and their sibling with developmental disabilities?
- Who among the siblings take what responsibilities, and how does that affect the sibship relationships?

The research conducted thus far indicates that siblings occupy a pivotal position within the family, even when they do not live with parents who are the primary caregivers. Program administrators should anticipate the transfer of responsibility from parent to sibling as the family system ages. In fact, one of the biggest problems faced by persons with developmental disabilities as their parents age and are less capable of caring for them is the likelihood that their parents will not be discussing their long-term care plans with them, their other children, or service providers. Planning for the future may evoke psychological pain for families. It has been hypothesized that families experience sadness and sometimes grief when confronted with developmental transitions or other markers that differentiate the life of their family member with developmental disabilities from that which is normative. Siblings, too, may be sharing some of the same feelings of loss and sadness related to developmental milestones never achieved, such as marriage and bearing children. The absence of these milestones may also add to siblings' anticipatory stress in regard to their future and perhaps lifelong responsibility to their siblings with develop-

mental disabilities. Service providers who recognize these dynamics may be able to support opportunities for families to discuss residential placements or many other issues in long-term planning that otherwise may not emerge until some crisis occurs, such as the death or debilitation of a parent.

One of the pragmatic reasons that families are often discouraged from long-term planning is their perception that the service system changes, often in capricious ways. Policymakers are just beginning to recognize the need to creatively support living arrangements that give more control and choice to the persons with developmental disabilities and their families. In most states, there are long waiting lists for services, a problem that may be modified when policymakers and planners support options that promote home ownership by persons with developmental disabilities or perhaps jointly with their siblings. In spite of the psychological impediments to planning, families will engage in the planning process more often when there are more stable options for them to consider when they plan.

Since so little has been done in this area, it is easier to generate questions than report what is known. Three recently published books are important resources for those interested in this topic. *Brothers and Sisters: A Special Part of Exceptional Families*, by Thomas Powell and Peggy Ahrenhold Gallagher, includes chapters on siblings during adulthood. The second book, *The Effects of Mental Retardation, Disability and Illness on Sibling Relationships: Research Issues and Challenges*, edited by Zolinda Stoneman and Phyllis Waldman Berman, is an edited collection of articles, many of which focus on the conceptual and methodological issues related to research on sibling relationships. A third book, *Older Adults with Developmental Disabilities: Toward Community Integration*, is edited by Sutton, Heller, Factor, Hawkins, and Seltzer. This book includes many chapters related to long-term planning and the relationship of out-of-home placement to family involvement. It provides many innovative suggestions that can aid service providers and program planners in their work with siblings and parents. All are published by the Paul H. Brookes Publishing Company in Baltimore.

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Health Services for Older People with Mental Retardation/Developmental Disabilities

by Deborah J. Anderson and Patricia Moran

Traditionally, older people with mental retardation/developmental disabilities (MR/DD) have been placed predominantly in nursing homes or state institutions. However, the OBRA-87 mandated review of nursing home placements, the continued emphasis on community rather than institutional placement, and a renewed emphasis on family caregiving have resulted in increased demands on community residential care services for this population.

One of the critical issues in planning services for older adults with MR/DD is their health status, including the presence of various health conditions, the need for medical care, and the capability of residential service providers to care for health-related needs. A national study of older adults with mental retardation living in MR/DD licensed facilities - foster care, group homes, large private facilities, and state operated facilities - was conducted at the University of Minnesota in 1985-86 (Anderson, Lakin, Bruininks, & Hill, 1987). Three hundred seventy individuals from 235 facilities were studied. Information about resident characteristics, health status and health care, adaptive behavior, and other issues was obtained through surveys completed by caregivers. A follow-up study was conducted in 1990-91 with the original sample to determine whether changes had occurred in residents' health status and needs and/or caregiver practices. These studies provide some insight into the health status of and services received by older people with MR/DD.

In the original and followup studies of older people living in MR/DD licensed residential facilities, the most common chronic health problems were high blood pressure, arthritis, and heart disease (similar to the problems of this age group in general) followed by glaucoma/cataracts. The vast majority of residents had at least one chronic health problem. Alzheimer's disease, a frequent source of concern, was infrequently reported (0-3%). Although heart disease and arthritis showed a 10% increase over the four year period, the prevalence of chronic health problems generally did not vary significantly over time or by facility type.

However, the amount of medical care received varied considerably by facility type, with larger private and state facilities typically providing daily or 24 hour care, in contrast to foster care and group homes in which residents typically received care monthly or less often. To some extent, this appears to be due to institutional policy, and to some extent to the medical needs of individual residents. For example, the major health conditions did not differ across facilities, even though the intensity of care did, but some other

indicators (e.g., medical limitations) differed in the expected direction. Most residents were taking at least one medication, either prescribed or over-the-counter, for a health or mental health condition. The percentage of residents who were taking medications increased from 75% in the original survey to 85% in the follow-up survey, indicating a slight increase with age in health conditions requiring medication.

Foster care residents had the fewest medical limitations due to health problems, and residents of large private and state facilities the most. Even in state institutions, however, the majority, or about two-thirds of residents, had few or no limitations. Thus, this group is fairly healthy, despite their advanced age.

About one in five residents in the followup study had been hospitalized in the year prior to the study, the majority being hospitalized only once. A minority of providers indicated that they had encountered problems in finding or getting appropriate medical services for the resident. Among those having problems, the most commonly cited problem was that medical professionals would not accept the reimbursement rates. Nonetheless, residents saw a medical doctor eight to nine times during the year on the average, and a dentist twice per year.

Careproviders frequently indicated that they had noticed changes in the resident related to the aging process. One of the most frequent age-related changes cited was that the resident had less energy and stamina. Also often indicated were physical and health changes such as general health decline, problems in walking/arthritis, skill changes, and cognitive changes.

To a lesser extent, careproviders noted that residents' service/support needs had changed because they were getting older, particularly in large private facilities. This increased significantly over the two time periods, with twice as many careproviders indicating changes in the follow-up study as in the original study. In addition to age, about one-third of community residential staff noted other factors that had influenced residents' support/services needs either positively or negatively in the past four years. These factors included changes in health status, decline in family contact, or residential or day program changes.

Overall, the responses to health-related questions suggest that although routine health care did not seem to be problematic for most, there often was little planning or capability for handling emergencies. In addition, many residences seemed to have difficulty managing mobility limitations.

These findings raise a number of issues. The health

status of those adults with MR/DD who are in their 60s and 70s appears to be, for the most part, considerably better than many have expected, and very comparable to individuals without MR/DD living in the community. The lack of planning for ways of responding to health emergencies in community settings places older adults at risk for nursing home placement due to the facility's inability to handle mobility limitations, to provide extra staffing when needed, and/or to handle the other aspects of medical care, such as transportation.

Some encouraging changes were evident over the time period of the two studies, however, including an increasing awareness of the needs, rights, and even existence of older adults with MR/DD. In the original study period (1985-86), there were few programs specifically for this age group, staff training in aging and developmental disabilities was minimal, and the most frequent placement for older people with mental retardation was a nursing home. In general, little was known about this age group, and stereotypes abounded, even

among caregivers. By 1990, a large variety of research and other efforts which centered upon the older population were ongoing. OBRA-87 had been enacted, and programs and activities were in existence to accommodate the special needs of this population.

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Psychotropic Drug Use Among Older Persons with MR/DD

by Deborah J. Anderson and Barbara Polister

One of the least understood areas concerning people who have mental retardation/developmental disabilities (MR/DD) is the use of mind-altering (psychotropic) medications to treat psychoses, anxiety, depression, and other mental conditions. There is little research on the prevalence and effects of psychotropic medications among people with developmental disabilities. Existing research has dealt almost exclusively with children and young people, who may be expected to respond differently from older adults. Only a handful of studies on medications have been conducted in community residential settings, the settings where most people with developmental disabilities live.

Studies of the prevalence of psychotropic medication use among older people with MR/DD report widely differing findings. For instance, international comparisons of the prevalence of antipsychotic medications for people with MR/DD indicate they are used more sparingly in Europe, Australia, and New Zealand than in the United States. Studies have concluded that about half of the drug regimens for persons with MR/DD in this country are inappropriate for the conditions diagnosed, and that most are prescribed by physicians rather than psychiatrists. For instance, a University of Minnesota study, using a national sample, found that the majority of older adults with mental retardation who were prescribed antipsychotic medication were not psychotic, but had less serious mental health or

behavior problems. The study also found that residents of large private facilities were most likely to be prescribed antipsychotics and other mind-altering drugs (e.g., tranquilizers, sedatives, antidepressants), followed by group home residents; those least likely to be taking such drugs were living in foster care and state institutions.

Excessive use of psychotropic medications can affect people in a variety of ways. Side effects from these drugs often interfere with community integration. Some side effects are long-term and irreversible. Older adults are more likely to be taking multiple drugs, and some drugs have cumulative side effects that appear only after many years of use. In addition, as people age the ability to metabolize and eliminate drugs decreases, so dosages appropriate for younger adults may be toxic for older adults.

Given the problems with the use of these medications and the difficulties involved in assessing their effects on this population, careful monitoring and research to determine effectiveness for different problems is essential.

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Health Issues for Aging Persons with Down Syndrome

by Marilyn Adlin

Life expectancy for persons with Down syndrome has increased dramatically over the past fifty years. In 1929, it was 9 years; in 1961 it had increased to 18.3 years, and today it is approximately 55 years. The primary reasons for this increase are improvements in health care and greater opportunities for community living. While individuals with Down syndrome are living longer than ever before, they do experience many of the changes associated with aging at an earlier age than the general population. Awareness of these changes and early intervention may help to reduce disability and preserve optimal functioning.

- **Alzheimer's Disease:** Approximately 40% of persons with Down syndrome develop the dementia symptoms associated with Alzheimer's disease. The average age of onset of symptoms in individuals with Down syndrome is 53-55 years. The changes in the brain associated with Alzheimer's occur in all persons with Down syndrome beginning at the age of 40. It is not clear why 60% of individuals with Down syndrome appear to be resistant to developing dementia despite these brain changes. There are reported cases of some individuals with Down syndrome living to the age of 85 without developing signs of dementia.

The duration of Alzheimer's dementia has been reported to be 3.5-10.5 years from diagnosis until death in persons with Down syndrome. Early symptoms include memory loss, getting lost in a familiar environment, and decreased verbal expression. Later signs can consist of apathy, inattention, decreased social interaction, daytime sleepiness, gait deterioration, muscle spasms, and seizures. It is possible, however, that these signs may be incorrectly attributed to Alzheimer's. Sleep apnea, sensory losses, other diseases, and general discomfort may cause some of these same signs. Behavioral changes and functional declines may also be due to depression, an adjustment reaction to an environmental change, and a limited capacity to express emotional states due to lack of education rather than Alzheimer's disease.

- **Hearing Loss:** Persons with Down syndrome are more likely to develop a problem with hearing as they get older. Many acquired hearing loss in childhood due to middle ear infections. Beginning as early as their 20s, persons with Down syndrome are prone to the same type of hearing loss experienced by the general elderly population. This results in a loss in the ability to hear higher pitched sounds and difficulty distinguishing sounds, especially when there is background noise present.

- **Vision:** Approximately 50% of adults with Down syndrome develop cataracts. Visual impairment, especially when combined with the higher rates of hearing loss and

dementia, can markedly interfere with the ability to negotiate the environment and may contribute to observed functional or behavioral declines.

- **Thyroid Disease:** Hypothyroidism occurs in 20-30% of persons with Down syndrome. Symptoms include lethargy, functional decline, confusion, constipation, dry skin and hair, fatigue, and depression. If untreated, it can lead to hallucinations and coma.

- **Sleep Apnea:** Obstructive sleep apnea has been reported in both children and adults with Down Syndrome. Predisposing factors among those with Down syndrome include: abnormally small upper airway, increased secretions, obesity, decreased muscle tone causing a collapse of the airway, tongue weakness, and enlarged adenoids and tonsils due to frequent infections. Symptoms include excessive daytime sleeping, behavioral disturbances, failure to thrive, declining functional skills, and disrupted sleep pattern. In the general population the prevalence of sleep apnea has been noted to increase with age. Since persons with Down Syndrome have so many predisposing factors we would expect to see an increase in the prevalence of obstructive sleep apnea among individuals with Down syndrome as they age.

- **Heart Disease:** Congenital heart disease occurs in 40% of persons born with Down syndrome. Repairs of most cardiac lesions are now routinely corrected within the first year. It is unclear if this group will have special needs as they get older. Adults with Down syndrome may develop heart murmurs that were not present at birth, as well.

- **Musculoskeletal:** Individuals with Down syndrome often have abnormalities including decreased muscle tone, lax ligaments, curvature of the spine, and hip problems. All of these conditions can impair mobility and limit activities in later life, particularly when arthritis develops. In addition, up to 90% of persons with Down syndrome have bunions which can cause difficulties with walking and balance.

Regular screening and early treatment for the conditions noted above will allow individuals with Down syndrome to maximize their functional capacity as they grow older.

Marilyn Adlin is Assistant Professor with the Institute on Aging and Adult Life, University of Wisconsin, Madison.

Programming for Persons with Alzheimer's

by Bill Everett

Alzheimer's disease is a dementia or condition marked by the decline of mental abilities. Individuals with mental retardation/developmental disabilities (MR/DD) and Alzheimer's have needs that may differ from those of other older persons with MR/DD. Awareness of these needs and strategies for responding are essential for those providing services to the aging MR/DD population.

Characteristics frequently associated with Alzheimer's that may require modifications in facilities, programming, and staff responsibilities are disorientation, confusion, forgetfulness, difficulty finding words to express thoughts, difficulty remembering the meanings of words, aggression, hostility, difficulty moving about, decreased sense of control over their life, and decreased self esteem. There are a number of ways to accommodate these traits and enhance the lives of persons with Alzheimer's, including:

- **Staff Training:** Teach staff about the characteristics and needs of persons with Alzheimer's, and the program implications. Strive for consistency in staff members' approaches and expectations in working with clients.

- **Facility Evaluation:** Evaluate your facility according to licensing regulations. Look at evacuation demands, staffing, supervision levels, floor plans, traffic patterns, lighting, and privacy. Identify modifications that can be made to allow persons with Alzheimer's to remain there. If the facility is unable to accommodate a person in the present setting, consider a change in placement.

- **Skill/Activity Maintenance:** Encourage daily use of participant's remaining skills. Persons with Alzheimer's gradually lose the ability to learn new tasks, so focus on familiar tasks. Identify and use motivators, and praise the individual for success.

- **Communication Adaptation:** Use communication techniques that fit the person's increasingly impaired communication abilities. Allow time for information to be absorbed. Repeat instructions consistently.

- **Health Monitoring:** Establish a diagnostic workup and frequent

checkups with routine follow-up. There will be reduced ability to report pain and illness, so observe the individual very closely. Prevent deterioration in ambulation by encouraging exercise.

Program interventions for persons with MR/DD and Alzheimer's must be carefully planned and integrated into an environment whose physical and social characteristics enhance the individual's functioning. Service providers can begin this process by learning more about this population and how to meet its needs.

Bill Everett is Director of Programming and Training at Northeast House, an ICF-MR residential setting for aging persons with MR/DD in Minneapolis.

"I Hate Friday Nights!"

"I hate Friday nights . . . boring, boring, boring . . . Why can't this be Monday morning?" It was a very loud, convincing announcement that was made by a person with developmental disabilities who was preparing for her bus ride home, and one of the finest affirmations any day program can receive!

AlterCare, Inc., is a unique program developed in 1985 to provide specialized day programming specific to the needs of people with memory loss. Initially, including adults with developmental disabilities and dementia was not anticipated. Because of the insistence and creativity of a county social worker looking for alternative day programming, we agreed to integrate our first person into the program on a trial basis. One day later this participant's "best friend" joined her and continues to attend daily.

AlterCare is a free-standing, non-profit organization. The center has colorful surroundings, comfortable furnishings, dining areas, private spaces for calmness and personal care, and places to move about without feeling confined. Photos, flowers, afghans and other objects make the atmosphere homelike. The center staff include a recreational specialist, occupational therapist, registered music therapist, nurses, nursing assistants, and program aides. All staff members are involved in direct care and are required to participate in ongoing educational training programs to grow more specialized and to look for new approaches. Center activities are fun, consistent, and build self-esteem.

Most of the participating adults with developmental disabilities are young when compared with our average mid-late 70s group. This has for the most part been an unexpected advantage, offering special opportunities to form intergenerational relationships similar to ones they may have had with parents while living at home. We have found them to be very much involved in serving and helping each other.

The philosophy of AlterCare is to provide a comforting, secure environment, taking into account changes that occur with aging and memory loss. Taking care of people with memory loss can be rewarding. Success can come in surprise packages -- even on Friday afternoons.

By Beverly Colson, Co-Founder of AlterCare, located in Edina, Minnesota.

Resources

The following organizations and materials provide information on the issues, needs, and concerns of aging persons with developmental disabilities and their families. Information on cost and ordering procedures for publications should be obtained by contacting the publishers of the materials.

■ Organizations

- **Aging/DD Clearinghouse.** 159 Carroll Hall, The University of Akron, Akron, OH 44325-5007 • (800) 538-6544. Contact: Ruth Roberts. Provides information and referrals related to older persons with developmental disabilities. Sponsored by the RRTC Consortium on Aging and Developmental Disabilities.
- **RRTC Consortium on Aging and Developmental Disabilities.** University Affiliated Cincinnati Center for Developmental Disorders, 3300 Elland Avenue, Cincinnati, OH 45229 • (513) 559-4958. Contacts: Esther Lee Pederson and Tom Lottman. Conducts research, training, and information dissemination.
- **The National Down Syndrome Society.** 666 Broadway, New York, NY 10012 • (800) 252-NDSC. Provides information on Down syndrome and Alzheimer's disease.

■ Publications

- **The Wit to Win: How to Integrate Older Persons with Developmental Disabilities into Community Aging Programs.** By P. LePore and M. Janicki. A guide for service providers in both aging and developmental disability networks about ways to help older adults with developmental disabilities find and use generic community programs for senior citizens. Available from the New York State Office for the Aging, 2 Empire State Plaza, Albany, NY 12224-0001 • (800) 342-9871.
- **Aging and Developmental Disabilities: Challenges for the 1990s.** Proceedings of the Boston Roundtable on Research Issues and Applications in Aging and Developmental Disabilities. Available from Matt Janicki, NYS Dept. of MR/DD, 44 Holland Avenue, Albany, NY 12229-0001.
- **Models for Interagency Planning for Long-Term Funding of Small-Scale Community Living Options for Older Persons with Developmental Disabilities.** By M. Martinson and J. Stone. A monograph on interagency planning models that integrate value-based planning, options for small-scale community living, and fiscally efficient long-term funding. Available from the Interdisciplinary Human Development Institute, University of Kentucky, Mineral Industries Bldg., Room 330, Lexington, KY 40506-1901.

- **Older Adults with Developmental Disabilities: Optimizing Choice and Change.** Edited by Sutton, E., Factor, A., Hawkins, B., Heller, T., and Seltzer, G. Published by Paul H. Brookes Publishing, Baltimore. A collection of recent articles on issues in aging and developmental disabilities written primarily by members of the RRTC Consortium on Aging and Developmental Disabilities. Publication expected spring, 1993.

The following are available from the RRTC Consortium on Aging and DD, through the Institute on Life-Span Development and Gerontology, The University of Akron, 179 Simmons Hall, Akron, OH 44325-4307 • (800) 838-6544, (216) 972-7243.

- **A Resource Guide for Training Specialists in Aging and Developmental Disabilities.** A research-based manual that provides a framework for training at preservice and inservice levels. Includes instructor objectives, training outline, training resources, and materials suitable for use as handouts and overheads.
- **Research Briefs.** Executive summaries of the work of RRTC Consortium on Aging and Developmental Disabilities researchers at seven universities. Topics include fiscal and program policy analysis, community service delivery, funding for family-sized community living options, age-related physical changes, behavior capabilities assessment and intervention strategies, and others.
- **Peer Companion Model Implementing Community Integration for Older Persons with Developmental Disabilities.** Addresses recruitment of nondisabled senior volunteers community integration facilitators for older persons with developmental disabilities.

The following are available from the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455 • (612) 624-4512.

- **IMPACT:** Feature issues on the ADA and People with Developmental Disabilities, Training of Direct Service Staff, Self-Advocacy, and Family Empowerment.
- **Policy Research Brief: Waiting for Community Services - Support and Service Needs of Families with Adult Members Who Have MR/DD** (1992). Summary of study documenting impact of waiting for services on adults with MR/DD and their families.



Edge, cont. from page 1

my learning levels are as high as 12th grade.

Sometime before I reached 39, I thought about forcing my parents to institutionalize me. Back then my parents and I thought that a person with a severe disability had to live their lives with parents, relatives, or be institutionalized and warehoused for the rest of their lives. Neither

my parents or I knew that there were programs that enabled people with severe disabilities to live in community settings. When I was 39 my parents were getting in poor health, so I decided to force them into institutionalizing me. Basically, I did this for two reasons: the first one was because of their health and the fact that I did not want to be a burden on them anymore. The second reason was that I was getting up in age and before I died I wanted to be around people my own age.

What I am going to say next is very personal and I don't like to talk about it, but if I do it might save untold thousands of my disabled brothers and sisters and their parents the heartache that my parents and I went through. The way I did it some people might think was cruel, but I did it the only way I knew how. I decided to go to bed and not get up, not eat, and not drink anything until my parents put me in an institution. In the beginning, my mother said that this is one of his spells that he is going through, but when she and my other family members saw that I wasn't eating or drinking anything she really got upset. Every day one or two of them would try to talk me out of it. Mother began to call different agencies, about 50, but they wouldn't touch the problem with a 10 foot pole. After another four or five days, my mother decided that I had lost my mind and took me to University of Louisville Hospital. They put me behind locked doors in the psychiatric ward for 10 days for observation.

While I was in this hospital I got lucky. The doctor who was assigned to my case was both a medical and a psychiatric doctor and she took the time to find out that I was not mentally sick and that I had intelligence. She took the time to call about 50 more agencies to see if I could get help so that I could live in the community independently. In fact, she introduced me to my first linguistic board. Just think of this, neither my mother nor I thought of such a simple thing as a letter board so that I could communicate on my own. When she introduced this thing to me it opened up a whole new world to me because only two or three of my family members could understand my speech.

One day she came to me and said that she might have found an agency that would help me to gain my independence. This agency was called the Center for Accessible Living and was a network of independent living centers

throughout the nation. The center's mission was to provide an environment that supports people with disabilities to attain as much independence as possible. With the assistance of this agency and several others, I have been living independently on my own for nine years. I am able to do this with the help of several programs, including personal care attendants who provide personal assistance like dressing, bathing, preparing meals, and housekeeping.

Prior to moving out on my own, I did not know that there was a disability movement in the world. In fact, I had never been around another person with a disability. As a result, when I first started to work with people with disabilities I felt uncomfortable and out of place. After working on many disability issues with people having many disabilities and their organizations, I have come to love my disabled brothers and sisters. More than that, I have come to respect them. In fact, I have decided to dedicate the rest of my life as a civil rights worker in the field of disability.

I've been involved in many committees, boards and councils. When I first got on these councils and boards there was no support system in place. I had to have an interpreter/attendant in order to participate, and most of the time I used a mobilized wheelchair. The agencies told me that I had to make all the arrangements and pay my assistant out of my pocket and then they would reimburse me about three months later (remember my income and my speech impairment). I can say it has gotten somewhat better, but not much.

People who sit on these committees are usually well meaning people. However, many have a different agenda from their disabled sons and daughters or clients. They have their own interests and when one person with a disability on their boards keeps bringing up issues that they don't really see as important, they write it off as one person with a disability expressing his opinion. I have come home from meetings many times so depressed that I question myself, "Should I resign and let some other person with more ability than I have take my place and try to convince these council members about what the disabled population really needs?" But then I look around and wonder who would put up with this frustration and I don't see anyone. Something within me won't let me drop out, so I am always on the edge.

Within the last nine years I have helped fight for many programs and community-based services like personal care attendants. Right now I am using up my personal care time to write this article because there are no more systems for me to use to take part in betterment of my people. This is unfair to both myself and my assistant. What is worse is that I and every other severely disabled person are right on the edge of being confined in a state concentration camp because disability community is devalued by our society and government. So, unless we, the disabled community, take part in the decision making process, we will always be on the edge.

Arthur Campbell, Jr., is a "disabled activist and practitioner of civil disobedience on behalf of my disabled brothers and sisters." He lives in Louisville, Kentucky.

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